

ORIGINAL ARTICLE

Is it possible and worth keeping track of deaths within general practice? Results of a 15 year observational study

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Aim: To assess the value of maintaining a death register in a general practice with particular reference to monitoring quality of care.

Design of study: Observational study.

Setting: Inner London general practice.

Method: The practice maintained a manual death register, retained medical records of all deceased patients, and requested information on cause of death from health authorities and coroners for 15 years.

Main outcome measures: Number and causes of deaths; 3 yearly age standardised death rates; proportion of deaths formally notified to the practice; place of death; source of cause of death information.

Results: During the study period 578 patients died. Practice age standardised death rates fell significantly from 35.59 to 27.12/1000. 498 (86.2%) deaths were formally notified to the practice, 392 within 7 days of death. Of 143 deaths reported to the coroner, only 45 coroners' reports were received. 360 (64.1%) died in hospital, 139 (24.8%) at home, and 38 (6.8%) in a hospice. Death certificate cause of death information was obtained from patients' records in 33.6% (n=194) of cases and from health authority sources for 50% (n=289). The pattern of ascertained causes of deaths was similar to the national pattern.

Conclusion: A death register can examine trends in practice deaths by age and place of death and comparisons undertaken with nationally published mortality data. An accurate picture of cause of death cannot be generated from routine data flows alone. There is delay in informing GPs of patient deaths. Meaningful and timely monitoring of deaths cannot be undertaken by individual practices. National Statistics should provide routine analysis of GP death certificate information.

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Patterns and rates of mortality provide important evidence of healthcare outcomes. Since the first published analysis of deaths in a UK general practice,¹ subsequent studies have examined several aspects of death registers in primary care.^{2–14} Studies have focused on critical incident analysis,⁸ bereavement protocols,^{9,10} the legacy of deaths in general practice,¹¹ hospital communication to GPs,¹² communication of autopsy findings to GPs,¹³ and use of practice level mortality data to inform health needs assessment.¹⁴ Death registers have been found valuable in monitoring and improving quality of care,^{2–4} and practice based audits of preventable deaths have been found educational and a source of ideas for service improvements.^{5,6}

Primary care trusts (PCTs), charged with establishing systems for clinical governance that monitor effectively the quality of care provided to their populations,¹⁵ are currently examining whether practice level information on mortality can provide reliable markers of primary health care quality (box 1). The recent conviction for multiple murders of the GP Harold Shipman and subsequent enquiries into how his crimes remained undetected over a 23 year period bring new urgency to monitoring deaths in general practice (box 2).^{16–18} In this paper we present findings from an analysis of a general practice death register maintained over a 15 year period and examine its potential to contribute to clinical governance at practice and PCT level. Whether a register of deaths offers relevant information for monitoring quality of care depends on whether it can be compiled from routinely collected data that allow a practice to undertake meaningful clinical governance in relation to practice mortality (box 3).

METHODS

The study was carried out between August 1985 and July 2000 in an inner London practice with an initial list size of 2545, rising to 4900 during the study period (box 4). With an age/sex structure comparable to that of the population of England and Wales, our patient population resides in one of the more deprived areas of the country, 90% on the ward basis and 68% on the enumeration district basis attracting deprivation payments.²¹ Throughout the study period the practice recorded quarterly list size by age bands (0–64, 65–74, over 75 years) as routinely notified to us by the health authority, maintained a manual register of deaths and, with agreement of local health authorities, retained the medical records of all deceased patients.

Box 1 Definitions

UK Primary Care Trusts: primary care organisations established in the National Health Service in 1997, responsible for provision of primary care services and for commissioning health services from other community and hospital trusts.

Clinical governance: a framework through which National Health Service organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment which will promote excellence in clinical care.

Box 2 Dr Harold Shipman

- Harold Frederick Shipman was a UK general practitioner who first became a GP in Todmorden, West Yorkshire in the mid 1970s and later practised in Hyde, Greater Manchester.
- Not long after he started in practice Dr Shipman was arrested on prescription fraud charges; he pleaded guilty to eight offences and asked for a further 75 to be taken into account. The method he used then to procure pethidine for himself he continued to deploy (undetected for some 23 years) to procure diamorphine: overprescription of the drug to patients who clinically needed it, keeping the excess for his own unlawful purposes.
- After the prescription fraud conviction Shipman was disciplined by the General Medical Council (GMC) but not debarred from practice. He received psychiatric treatment and shortly afterwards became a GP member of a group practice in Hyde. Some years later he took charge of a nearby single handed practice.
- In September 1998 Dr Shipman was arrested and charged with the murder of 15 of his patients, and with forging a will. He was convicted at Preston Crown Court in January 2000 and sentenced to life imprisonment and erased from the GMC register on 11 February 2000.
- In each instance Shipman's method of murder seems to have been by administration of intravenous diamorphine, either in the victim's own home or on his surgery premises. Many of his patients who died at home were found sitting upright in a chair with a sleeve rolled up. His motive for serial murder has remained mysterious; except in the case of his last victim, whose will Shipman transparently altered (he retyped it on his own typewriter and made himself sole legatee), it does not seem to have been financial gain (although he is reported to have stolen jewellery).
- A review covering the period 1974–1998 compared clinical notes on patients who died while registered with Shipman with clinical notes on patients who died while registered with comparable local practices.^{16 17} The review concluded that excess deaths in Shipman's practice numbered 236 (95% CI 198 to 277). It found that Shipman had been present at 19% of deaths compared with a GP presence of 1% at deaths in comparator practices, and that relatives and carers were less likely to have been present (40.1% v 80%) at his patients' deaths than at deaths in comparator practices. Deaths in Shipman's practice peaked between 13.00–18.00 hours (12% died around 14.00 hours, the time when Shipman undertook home visits, compared with 2% in comparator practices), and in Shipman's practice the proportion of people who died quickly (in less than 30 minutes) was nearly three times that in comparator practices. Final assessment of the Shipman case must await the findings of the Judicial Inquiry¹⁸ currently looking into his activities, but it has already concluded that Shipman unlawfully killed patients in each of the three practices in which he worked, with a total over his working life of 220–240.
- Very few UK doctors have been found guilty of murdering their patients,^{19 20} but the Shipman case has highlighted the possibility of systemic failure in UK civil procedures surrounding death certification and registration, including:
 - how he managed to avoid referral of many unexpected deaths to the coroner (who seems to have accepted Shipman's use of "old age" as a cause of death in a high percentage of deaths);
 - failure of additional cremation certificate safeguards (the majority of Shipman's victims were cremated);
 - failure to detect Shipman's high death rate, particularly among women over 65;
 - failure to monitor and investigate the high proportion of death certificates signed by Shipman;
 - failure to detect and investigate the high proportion of home deaths and deaths on Shipman's practice premises (where no cardiopulmonary resuscitation was attempted and no emergency ambulances were called);
 - circumvention of the UK Misuse of Drugs Act 1971 and Misuse of Drugs Regulations 1985 which regulate prescribing of "dangerous" drugs, known as Controlled Drugs.

Box 3 How could a register of deaths contribute to GP clinical governance?

A register of deaths could allow a practice to:

- chart the demography of patient deaths over time;
- observe and compare practice death rates with national mortality rates;
- discern possible trends in place of patient death;
- track accurately the causes of death;
- become aware in a timely way of who has been bereaved.

Box 4 Characteristics of study practice**August 1985**

- 1 whole time equivalent GP
- No nursing assistance
- 1 part time receptionist
- 2545 patients
- Urban deprived area
- Above average morbidity

July 2000

- 2.75 whole time equivalent GPs
- 1 whole time equivalent practice nurse
- 6 administrative and reception staff
- 4900 patients
- Urban deprived area
- Above average morbidity

Box 5 Information fields in paper death entry forms

- Name, address, date of birth.
- Details of closest surviving relatives (including those not registered with the practice if contact details known).
- Date and place of death.
- Date the practice was informed of death, how it was informed, and by whom ("informal" notification referred to notification by a relative, neighbour, or local newspaper report; "formal" notification to notification by a health worker, social services, police, coroner, or health authority).
- Cause of death as advised by informant.
- Cause of death as stated on death certificate if available.
- Whether the death was investigated by the coroner and whether a coroner's report was requested by the practice and/or received.
- Whether there had been any domiciliary involvement by the terminal care team prior to death.

When we learned about a patient's death, a paper death entry form was completed with the information shown in box 5. At the end of the 15 year period a computer database was compiled, supplemented by reference to patients' notes. An additional field—date of last contact with the practice—was added, defined as consultation in the surgery, at home, a telephone call from a patient, or a community nurse contact.

Where there was no information about cause of death as recorded on the death certificate, the deceased patient's health authority of residence was asked to supply this information. Where death certificate information could not be obtained by these means, the underlying cause of death was inferred from information supplied when the death was notified to the practice, coded according to the International Classification of Diseases (ICD) 9th edition.²²

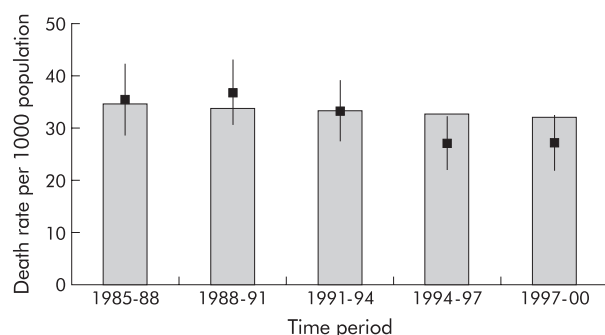
An attempt was made to estimate how many deaths may have occurred without our knowledge by undertaking a computer search to ascertain patients aged 65 and over who had not contacted the practice since February 1999 (when computer recording of consultations began). We wrote to 82 patients

Table 1 Three year age standardised practice death rates*

3 year period	No of practice deaths	Practice list size at mid point	3 year crude practice death rate/1000	Standardised 3 year practice death rate/1000 (95% CI)**	3 year death rate/1000 in England & Wales***
August 1985–8	105	3012	33.86	35.59 (28.66 to 42.51)	34.73
August 1988–91	131	3989	32.84	36.81 (30.44 to 43.19)	33.81
August 1991–4	121	3923	30.84	32.79 (27.33 to 39.19)	33.28
August 1994–7	106	4605	23.01	27.04 (21.87 to 32.22)	32.48
August 1997–2000	108	4864	22.20	27.12 (21.99 to 32.27)	31.78

*Date of death not known for 7 patients.

**Standardised (direct method) to England and Wales mid 1999 estimated population.

***Calculated from Office for National Statistics figures.²³ χ^2 test for trend in standardised 3 year death rate = 18.54, $p=0.00002$.**Figure 1** Three year age standardised practice death rates (with 95% CI) and national death rates 1985–2000.

who lacked computer evidence of practice contact over the preceding 18 months and received no response from 39. The relevant health authorities of residence were asked to search their databases for recorded deaths of these 39 people.

Permission for this work was obtained from the two local research ethics committees covering our practice area.

RESULTS

Demography of deaths

Five hundred and seventy eight patients were identified as having died during the study period, 296 (51%) of whom were female. No additional deaths were identified from the health authority search of selected patients ($n=39$). Only five of the 578 patients' medical records were missing and for these deaths the manual register was our only source of information. 438 patients (76.6%) who died were aged 65 or over at time of death, 88 (15.4%) were aged 45–64, 32 (5.6%) 25–44, and 14 (2.4%) were under 25 years. The exact date of death was unknown for seven patients but in one case age at death could be inferred.

Practice mortality and formal notification of deaths

Three year age standardised practice death rates fell significantly from 35.59/1000 in 1985/8 to 27.12/1000 in 1997/2000

(χ^2 test for trend = 18.54, $p=0.00002$; table 1), a fall suggestive of a steeper decline in practice than the national mortality rate over this period (fig 1). Informal notification of death (from relative, neighbour or newspaper report) was received for 238 patients (41.2%), and in 80 cases (13.8%) this was the only information received about the death. Formal notification of death was received for 498 patients (86.2%) from the following sources: hospitals ($n=280$, 56.2%), coroners ($n=71$, 14.3%), other health service staff ($n=40$, 8.0%), hospice ($n=38$, 7.6%), GP ($n=36$, 7.2%), health authority ($n=23$, 4.6%) the police ($n=8$, 1.6%), and unknown ($n=2$, 0.5%).

The percentage of patients for whom formal notification of death was received increased non-significantly from 84.8% in 1985/8 to 90.7% by 1997/2000 ($\chi^2=1.78$, $p=0.18$). Analysis of formal notification by place of death showed variation between local hospitals (highest hospital notification rate 94.5%, lowest 77.6%, $\chi^2=14.52$, $p=0.006$), while the notification rate from hospices was 100%, significantly higher than that of hospitals combined ($\chi^2=14.58$, $p=0.002$) (data not shown).

The interval between death and date of formal notification could be calculated for 491 patients and was within 7 days of death for 392 patients (79.8%), within 8–14 days for 60 (12.2%), and within 15–28 days for 30 (6.1%). For nine patients the time interval between death and notification ranged from 29 to 1606 days.

Place of death

The place of death and time trends in place of death are shown in table 2. During the study period 360 patients (64.1%) died in hospital, 139 (24.8%) at home, and 38 (6.8%) in a hospice. Twenty four "other" places of death included seven in the street, three abroad, three outside London, three in nursing homes, two on railway stations, one on a bus, one in a shop, and one in the river Thames. No deaths occurred on surgery premises. There was no significant trend in the proportion of deaths in hospital, home, or hospice over the 15 year period. Before death the domiciliary terminal care team was involved in the care of 72 patients (12.5%), over half of all those who died at home. According to the memories of the four GP principals responsible for the practice list over the study period, a

Table 2 Time trends in place of death (%)*

Date of death	Hospital	Home	Hospice	Other	Total
August 1985–8	67 (64.5)	23 (22.1)	6 (5.8)	8 (7.7)	104
August 1988–91	89 (69.0)	31 (24.0)	5 (3.9)	4 (3.1)	129
August 1991–4	68 (58.6)	32 (27.6)	8 (6.9)	8 (6.9)	116
August 1994–7	70 (66.7)	27 (25.7)	5 (4.8)	3 (2.9)	105
August 1997–2000	66 (61.8)	26 (24.3)	14 (13.1)	1 (0.9)	107
Total	360 (64.1)	139 (24.8)	38 (6.8)	24 (4.3)	561

*Information on 17 deaths insufficient to allow classification.

Death in hospital v elsewhere: χ^2 test for trend=0.36, $p=0.549$.Death at home v elsewhere: χ^2 test for trend=0.21, $p=0.649$.

Table 3 Frequency with which coroner's report received

Coroner's report	Frequency	%
Received unsolicited	4	2.8
Requested and received	41	28.7
Requested not received	65	45.5
Not requested not received	27	18.9
Verbal information only	6	4.2
Total	143	100.0

Table 4 Source of information about cause of death

Source of information	Frequency	%
Death certificate information in patient record	194	33.6
GP certification	52	
Information from other doctor	88	
Information from coroner	51	
Information from relative	3	
Death certificate information from HA	289	50.0
No death certificate details available	95	16.4
Formal cause of death used*	51	
Informal cause of death used**	13	
No cause of death information of any sort	31	
Total	578	100.0

*Formal=cause of death information from health worker, social services, police or coroner. **Informal=cause of death information from relative, neighbour or newspaper report.

GP had been present at the time of a patient's death or within 30 minutes or so of death in only four cases (0.69%).

Information was available about last contact with the surgery before death for 566 patients (97.6%): 45% (n=255) had had contact within a month of death and a further 19% (n=108) within 2 months of death. Five patients had never been seen at the surgery and five babies died in hospital around the time of birth.

Over the 15 year period 143 deaths (24.7%) were reported to the coroner, and this percentage remained similar throughout the study period (table 3). Despite a practice policy of writing to coroners to request reports, coroners' reports were received for fewer than one third of these deaths.

Causes of death

Table 4 shows how information about the cause of death was obtained for this study. Cause of death information from death certificates could be obtained from medical records in

Table 5 Cause of deaths in practice August 1985–July 2000

Cause of death (ICD codes)*	Frequency	%
Diseases of circulatory system (390–459)	215	37.2
Ischaemic heart disease (410–411)	108	18.7
Cerebrovascular disease (430–438)	52	9.0
Neoplasms (140–239)	141	24.4
Trachea, bronchus and lung (162)	42	
Digestive organs and peritoneum (150–159)	35	
Lymphatic (200–208)	15	
Bone, skin and breast (170–175)	14	
Diseases of the respiratory system (460–519)	85	14.7
Injury and poisoning (800–999)	27	4.7
Diseases of the digestive system (520–579)	23	4.0
All other causes	56	9.6
No information about cause	31	5.4
Total	578	100.0

*Underlying cause of death derived from death certificate information in 483 cases (88%).

Table 6 Closest surviving relatives of dead patients

Relationship to deceased	Frequency	%	Mean age at death
Child	164	28.4	77.7
Wife	126	21.8	68.9
Husband	60	10.4	68.6
Sibling	39	6.8	69.8
Other relative*	30	5.2	80.3
Parent	23	4.0	21.1
Friend/neighbour	13	2.3	68.7
Grandchild	5	0.9	88.0
None	64	11.1	78.3
Not known	54	9.3	74.4
Total	578	100	71.8

*Other relative=cousin, nephew, niece, aunt, stepdaughter, or sister-in-law.

only 194 cases (33.6%) but was obtainable from health authority sources for a further 289 (50%). No death certificate information was obtainable for 95 deaths (16.4%), and no information of any sort could be found about cause of death for 31 patients (5.4%).

The commonest causes of death are shown in table 5. The frequency of death from different causes is similar to that for England & Wales ($\chi^2=9.86$, $p=0.079$ (data not shown)). Twenty seven deaths were in the ICD category injury and poisoning, of which 15 (56%) were men; six were murdered, nine were killed in road traffic accidents (seven pedestrians, two pedal cyclists). Three deaths occurred from drug overdose, two in established drug users and the third in a naive user. Three patients committed suicide, two of whom had a schizophrenic illness. Half of the deaths from injury and poisoning occurred in patients aged under 45, but these causes contributed to only one third of the total deaths in that age group. Other important causes of deaths in this age group were HIV (n=7, all between 1990 and 1994), malignancy (n=7), and complications of intravenous drug misuse (n=4).

Bereavement

Twice as many men who died over this period widowed a wife than women who widowed a husband, although the mean age at death of both groups was the same (table 6). Twenty three patients (4%) who died left grieving parents. For 64 patients (11%) we could discern no surviving relatives at the time of their death.

DISCUSSION

It is 15 years since Julian Tudor Hart urged conscientious GPs to be their own coroners, to take on a local public health role and thereby to be more closely accountable to their population.¹ Over a 15 year period our practice register provided data about sufficient numbers of deaths to enable us to look at trends over time and to make simple comparisons with national data; a larger practice could expect to do so over a shorter period. But meaningful interpretation of our findings is difficult as death rates are influenced by many factors beyond health care delivered by a general practice. Nevertheless, cause of death findings highlight the large impact of circulatory disease and neoplasms upon mortality in an average sized UK general practice. Because deaths from common diseases are overshadowed in our memories by more dramatic and tragic deaths in younger patients, these findings serve as a powerful reminder to us of the importance of implementing preventive care in general practice, an approach that needs to go hand-in-hand with public health initiatives to control these conditions.

The majority of people represented by these data were personally known to us and received care of varying intensity and involvement within the practice and from hospital colleagues.

Four hundred and sixty left behind bereaved relatives and friends, many of whom were (and remain) registered with us.¹¹ This reinforces the importance of documenting bereavement in GP records and of making contact to offer support to relatives after a death. We were formally notified of death within 7 days in only 392 cases (68%); 87 (15%) were never formally notified to us.

UK general practice offers exceptional opportunities to observe, record, classify, and analyse clinical phenomena, but the extent to which this can be undertaken as part of service provision is limited. Our study shows that assembling a reasonably complete register of deaths is feasible—97.8% of ascertainable deaths were recorded by our register—but this could only be achieved with additional time and resources available from research funding. Practice computerisation now makes it administratively straightforward to establish templates to collect selected data on deaths, although such additional monitoring carries some resource implications. Our experience strongly suggests, however, that there are serious problems with the timeliness, accuracy, and completeness of information that can routinely be collected in this way.

The most important difficulty to be overcome by within-practice monitoring of deaths based on information usually supplied to GPs is in building up an accurate picture of causes of death. Sufficient death certificate information to allow us to assign the underlying cause of death was routinely made available to us from NHS and other sources in less than one third of cases, and this information was not based on the automated cause coding used by the Office for National Statistics to standardise assignment of the underlying cause of death.²⁴ Further problems were created by difficulties in obtaining cause of death information from certificates issued by coroners. After contacting coroners specifically to request this information, no report was provided on 68.5% of occasions, an experience similar to that reported from Manchester.¹⁴

A report from Newcastle, where the health authority introduced a system to provide GPs with automated cause coded information on deaths, suggested it was useful to practices with regard to administration, bereavement care, and medical audit.²⁵ The value of such a system would be enhanced if it enabled practices to compare trends in their practice with those in other practices within the PCT and nationally. However, to introduce such a system nationally in the first instance would require death certificates to be modified to include identification of the GP (GMC number, name or address) with whom the patient was registered at death.

Routine monitoring of mortality at practice level may be of limited value in detecting high death rates associated with poor practice because the expected number of deaths per year per GP is both small and variable.^{26–28} However, this does not exclude a role for practice level mortality monitoring in detection of seriously divergent (criminal) practices. A simple way to alert monitoring agencies to the possibility of significantly divergent practice as perpetrated by Shipman (box 2) would be to monitor place of death from mandatory precoded place categories, as collected by US and Japanese death certificates.²⁹ An unusually high number of deaths at home compared with the norm of a locality or any death on a surgery's premises should probably trigger some further investigation.^{14 15} Another variable worth tracking might be the percentage of a practice's total death certificates issued by GPs³⁰—over 15 years we issued only 52 of 578 (9.0%). In the USA and Japan information on time of death is routinely collected²⁹ which, if added to the UK certification process, could alert authorities to unusual patterns of mortality. It is not yet clear in the UK, however, whether aberrant behaviour and high normal variation can be monitored by one and the same system.¹⁷ The risk of creating “a statistical cacophony of false positive suspicion”²⁶ may already have occurred; since the Shipman conviction two GPs have been suspended pending

Box 6 Key messages

- This study shows that a register of practice deaths can allow GPs to:
 - chart the demography of patient deaths over time;
 - observe and compare practice death rates with national mortality rates;
 - discern possible trends in place of death.
- However, if a death register relies only on routinely provided data, notification of death may be too delayed to support appropriate care for bereaved relatives. Information on cause of death will be incomplete and inaccurate, which limits its clinical governance value for GPs wishing to use this information to identify preventable deaths and improve services.
- National Statistics should consider providing GPs with death certificate information and with analyses which make comparisons with PCT and national populations. This would require the addition of a GP identifier to the death certificate.
- Practice level mortality information could play a role in detecting divergent clinical practice if time and place of death and the percentage of certificates issued by the GP were routinely monitored to identify unusual characteristics. This would require further changes to information recorded on death certificates, in line with practices in the USA and Japan.

investigation of a possible association between deaths and opiate prescribing, but no unlawful activity has been proved.³¹

In our practice, establishing and maintaining a death register has been a useful learning exercise which clearly satisfied the first three purposes outlined in box 3. However, comprehensive maintenance of a register based on data routinely accessible to a general practice cannot meet the fourth purpose—to track cause of death. Varied sources of information, mixed reliability of cause of death information, and no cause of death data for 16.4% of deaths severely curtailed the monitoring value of a death register. In our experience, the fifth purpose—to become aware in a timely way of who has been bereaved—cannot be met either as notification of deaths to the practice was both too slow and incomplete. Accordingly, we now record only basic information: date and cause of death (if known) and the identities of bereaved relatives whom we contact soon after a death and again the following Christmas. In addition, patients who have died in the previous 6 months are discussed at a multidisciplinary practice meeting, a limited exercise which would significantly benefit from GPs routinely receiving standardised death certificate information about their deceased patients.

CONCLUSION

Monitoring of deaths within UK general practice is currently too complex a task to be undertaken by individual practices as part of their service responsibilities. National Statistics should consider providing GPs with death certificate information and with analyses of comparisons of PCTs and national populations. Simple changes to information recorded on death certificates—such as the inclusion of precoded place of death and a GP identifier—would facilitate making valid comparisons.

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